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Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder

LIVED EXPERIENCES OF THE ASSESSMENT AND DIAGNOSTIC PROCESS: SYSTEMATIC REVIEW AND QUALITATIVE SYNTHESIS REPORT

Corresponding Author	Natasha Reid, Senior Research Fellow, Child Health Research Centre, University of Queensland fasdguidelines@uq.edu.au; n.reid1@uq.edu.au
Research team:	Dr Natasha Reid, Ms Nicole Hewlett, Dr Nicole Hayes, Ms Chelsea Vanderpeet, Dr Lisa Akison, Dr Jayden Logan & Dr Nykola Kent
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Contents

Authors and contributions

Nicole Hayes	Shared responsibility for leading the design, conduct and reporting of the systematic review. Significant contribution to writing of the review report, study selection, study quality assessment, data extraction and synthesis and GRADE assessment.
Kerryn Bagley	Significant contribution to the writing of the review report, data synthesis and GRADE-CERQual ratings.
Nicole Hewlett	Significant contribution to the writing of the review report and data extraction.
Elizabeth Elliott	Contributed to the writing and critical review of the report.
Carmela Pestell	Contributed to the writing and critical review of the report.
Matthew Gullo	Contributed to the writing and critical review of the report.
Zachary Munn	Provided guidance on GRADE assessment and contributed to critical review of the report.
Philippa Middleton	Contributed to critical review of the report.
Prue Walker	Contributed to critical review of the report.
Haydn Till	Contributed to critical review of the report.
Dianne Shanley	Contributed to critical review of the report.
Sophia Young	Contributed to study selection and critical review of the protocol and report.
Nirosha Boaden	Contributed to study quality assessment and contributed to critical review of the report.
Delyse Hutchinson	Contributed to critical review of the report.
Natalie Kippin	Contributed to critical review of the report.
Amy Finlay-Jones	Contributed to critical review of the report.
Rowena Friend	Contributed to critical review of the report.
Doug Shelton	Contributed to critical review of the report.
Alison Crichton	Contributed to critical review of the report.
Natasha Reid	Guidance during all stages of the review and contributed to drafting the report. Oversight and communication with Project Steering Committee in development of the protocol.

Declarations of interest

All authors declare they have no personal, financial, or professional interests that could be interpreted to have influenced conduct or results of this systematic review.

Peer reviewed publication

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Summary: A systematic review and qualitative synthesis of the lived experiences of the assessment and diagnostic process for fetal alcohol spectrum disorder

What is the problem?

Individuals with lived experience of FASD hold expertise about their own lives and family needs. Understanding their perspectives on the assessment and diagnostic process for FASD are important for informing the provision of meaningful, person- and family-centred care.

What is the importance?

The results of the current review provide guidance for clinicians in managing referral pathways, ensuring client- and family-centred assessment processes, and implementing post-diagnosis intervention and support. Recommendations in any FASD clinical process to ensure caregivers and people with FASD are appropriately engaged and supported include identifying any pre-assessment concerns and challenges, considering a range of elements of the diagnostic assessment process, including the benefits and challenges of receiving a diagnosis, and engaging in post-assessment planning and adaptions. This will ensure the best quality care for people with FASD and their families.

What are the key findings?

Ten studies were included in the review. A thematic analysis identified ten themes in the lived experiences of individuals with FASD, which related to four over-arching topics: pre-assessment concerns and challenges, the diagnostic assessment process, receiving the diagnosis, and post-assessment adaptations and needs.

1. Background and rationale

The Australian Government funded a consortium to review, update, and disseminate guidelines for assessment and diagnosis of FASD. This systematic review was undertaken as part of the evidence review supporting the revision process. An overview of the full evidence review is provided in the Administrative and Technical Report. The current review focussed on understanding the lived experiences of individuals and caregivers of the FASD assessment and diagnostic process. Lived experience perspectives critically inform the design and development of clinical practice guidelines. This particularly applies to the assessment and diagnosis of FASD, where the evidence base provides important implications for managing referral pathways, ensuring client- and family-centred assessment processes, and implementing post-diagnosis intervention and support.

2. Objectives

To systematically review and synthesise the existing evidence on the lived experiences of individuals and caregivers who have undertaken a diagnostic assessment for FASD, with the purpose to provide supporting evidence for the review of the Australian Guide for the Assessment and Diagnosis of FASD.

Research Question

What are the experiences of individuals with FASD and their families of the assessment and diagnostic process?

Population, Interest, Context (PICo) Statement

Population	Individuals diagnosed with FASD and/or caregivers of individuals diagnosed with FASD
Interest	Experiences of the assessment and diagnostic process for FASD
Context	Any country

3. Methods

3.1 Protocol and registration

A systematic review protocol was registered with the International Prospective Register of Systematic Reviews (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=230542; PROSPERO Reference: CRD42021230542). The review was designed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Page et al., 2021).

3.2 Study inclusion and exclusion criteria

Inclusion criteria

Criteria for inclusion in the review included:

- published in English
- reported qualitative or mixed methods primary research
- reported lived experiences for individuals and/or caregivers of individuals with FASD
- reported at least one theme relating to the experiences of diagnostic assessment for FASD or receiving a diagnosis of FASD

Exclusion criteria

Articles were excluded if:

- the study assessed other participants (i.e., health professionals) and data from individuals or caregivers of individuals with FASD could not be extracted separately
- the study reported only on the experiences of living with FASD rather than the diagnostic assessment process of FASD or receiving a diagnosis of FASD
- publications were theses, conference proceedings/abstracts or literature reviews.

3.3 Search strategy

Six electronic bibliographic databases were searched from inception until February 2021, and updated in December 2022: PubMed, the Cochrane Library, CINALH, EMBASE, PsycINFO and Web of Science Core Collection.

Search terms used uniformly across databases included:

Alcohol-related terms: prenatal alcohol OR alcohol exposed OR fetal alcohol OR foetal alcohol OR fetal alcohol spectrum disorder OR foetal alcohol spectrum disorder OR fetal alcohol syndrome OR foetal alcohol syndrome OR static encephalopathy OR alcohol-related birth defect* OR alcohol-related neurodevelopmental disorder OR neurobehav* disorder AND alcohol exposed OR neurobehav* disorder AND prenatal alcohol

AND

Lived experience terms: lived OR living OR care* OR caring OR raise* OR parent* OR experience* OR perspective* OR challeng* OR impact* OR need* OR perceive OR daily life OR daily lives OR benefit* OR risk* OR positive outcome* OR negative outcome* OR advantage* OR disadvantage*

AND

Assessment and diagnostic process terms: assess* OR diagnos* OR evaluat* OR clinic OR service OR system OR health care OR support OR screen*

Retrieved references were imported to an Endnote library and duplicate records were removed. References were then uploaded to Covidence systematic review software. Title and abstracts were independently screened for eligibility against inclusion and exclusion selection criteria by two reviewers. Full-text publications of the remaining references were then retrieved and independently assessed by two reviewers. Discrepancies were resolved via discussion with a third reviewer. Manual screening of reference lists of retrieved full-text publications was performed to identify relevant publications not identified by the initial search strategy.

3.4 Data extraction

Data were extracted from each study using a standard form that included article information (author, year, country), stated aim, study design, study population and relevant key findings including stated themes and sub-themes.

3.5 Assessment of risk of bias for included studies

The Critical Appraisal Skills Programme Checklists for Qualitative Studies (CASP, 2021) was used to assess risk of bias for included studies. The CASP Checklists consider study aims, methodology, participant-researcher relationships,

ethical issue, recruitment, data collection, data analysis, findings and research value. Items are evaluated as 'Yes', 'Partial', 'Unsure' and 'No'.

3.6 Data analysis and synthesis methods

A thematic approach was used to synthesise data (Thomas & Harden, 2008). Major themes, sub-themes, and supporting participant quotes related to lived experiences of the assessment and diagnostic process were extracted from each article. Extracted data was read line-by-line and coded, with common emerging codes grouped to form first-level themes. Themes were then categorised into over-arching topics.

3.7 GRADE-CERQual assessment

The Grading of Recommendations, Assessment, Development and Evaluation (GRADE)-Confidence in the Evidence from Reviews of Qualitative Research (CERQual) was used to assess confidence in the evidence (Lewin et al., 2015). CERQual provides an assessment of the extent to which each review finding is a reasonable representation of the phenomenon of interest. Evidence quality assessments are based on four components: methodological limitations, relevance, coherence, and adequacy of the data. Concerns about evidence quality on each component are rated as: no/very minor, minor, moderate or serious. Overall confidence has four levels: high, moderate, low, or very low. Review findings start as 'high confidence' and are rated down by one or more levels if there are concerns related to any of the four components.

4. Results

4.1 Search results and included study characteristics.

Search results are presented in Figure 1. Study characteristics and risk of bias ratings of included studies are presented in Tables 1 and 2. A list of studies excluded at full-text screening are presented in Appendix 1.

4.2 Review findings and GRADE CERQual assessment

The thematic analysis identified 10 themes in the lived experiences of the assessment and diagnostic process for FASD that relate to four over-arching topics: 1) pre-assessment concerns and challenges, 2) the diagnostic assessment process, 3) receiving the diagnosis and 4) post-assessment adaptations and needs.

A summary of these 10 themes and associated GRADE-CERQual assessments are presented in Table 3. A detailed summary of GRADE-CERQual assessment of confidence in the evidence ratings is provided in Table 4.

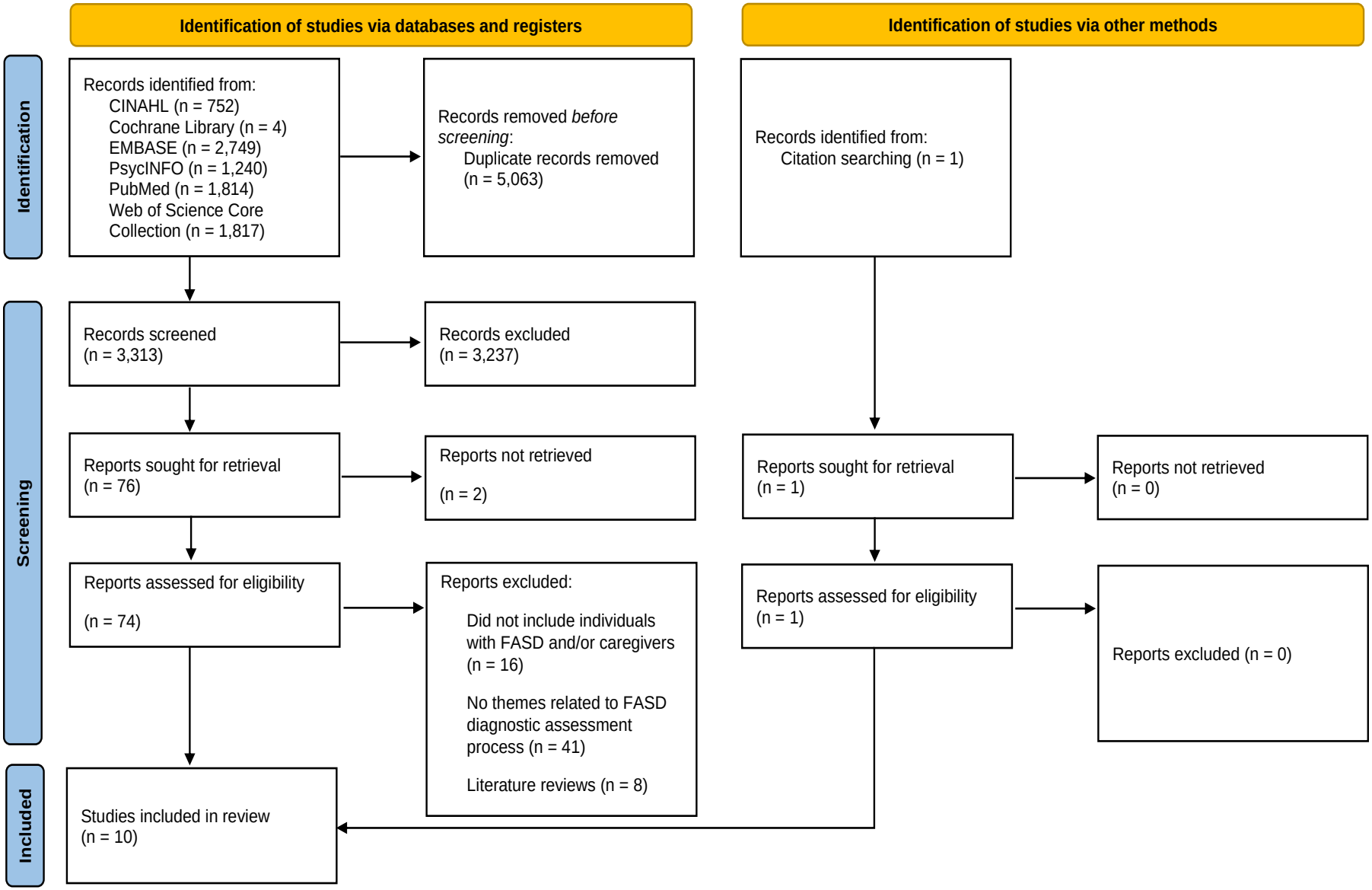

Figure 1. PRISMA flow diagram for the selection of studies.

Table 1. Study characteristics of included studies.

Author(s) (Year), Country	Research Aim	Participants	Data Collection and Analysis Methods	Relevant Study Themes[a]
Chamberlain et al. (2017) **Australia**	Explore the lived experience of the diagnostic process for caregivers of children with FASD	10 primary caregivers (4 foster parents; 1 adoptive parent; 5 legal guardians) of children (aged 6-12 years) who received a FASD diagnosis from a multidisciplinary specialist diagnostic service	Semi-structured interviews; phenomenological approach and thematic analysis	1. Caregivers' aspirations and actions to enhance their child's future 2. Increased caregiver uncertainty 3. Caregiver knowledge and understanding of FASD 4. Lack of societal knowledge and recognition of FASD 5. Assessment provided validation and understanding 6. Process of diagnosis as empowering
Doak et al. (2019) **Australia**	Explore the lived experiences of Australian caregivers who received a FASD diagnosis for a child in their care.	7 caregivers (3 biological mothers, 1 biological father, 1 maternal grandmother and 2 paternal grandmothers) of children (aged 3-13 years) who attended a specialist multidisciplinary FASD clinic and received a FASD diagnosis (n = 6) or an at risk of FASD diagnosis (n = 1).	Semi-structured interviews; phenomenological approach and thematic analysis	1. Receiving a FASD diagnosis had a positive impact 2. Caregivers' evaluation of assessment process 3. Positive support services relative to FASD 4. Ongoing difficulties regardless of diagnosis 5. Need for societal knowledge of FASD
Duquette and Stodel (2005) **Canada**	Gain an understanding of the school experiences of children with FASD and to identify the elements of a successful school experience from the perspective of children with FASD and their parents.	11 adoptive parents (middle class from the cultural majority) of an individual (aged ≥ 9 years) with FASD	Questionnaire with open-ended questions and semi-structured interviews; Grounded theory, qualitative analysis	1. Obtaining a diagnosis

Hamilton et al. (2020) **Australia**	Explore experiences of FASD diagnostic assessment among caregivers of detained young people.	15 caregivers (2 couples, 6 mothers, 5 grandmothers; 10 Aboriginal and 5 non-Aboriginal caregivers) of young person (aged 10-17 years) who received a multidisciplinary FASD diagnostic assessment as part of a larger FASD prevalence study among sentenced, detained youth.	Yarning; ontological approach with interpretivist lens and thematic network analysis	1. Conceptualisation of diagnosis 2. Diagnostic reports and resources 3. Post-diagnosis support
Petrenko et al. (2014) **U.S**	Examine system-level barriers that contribute to the development of secondary conditions in FASD	25 parents (1 biological mother, 24 adoptive/foster parents) of individuals (aged 3 to 33 years) with FASD.	Individual interview or focus groups; Phenomenological approach using framework analysis.	1. Delayed diagnosis 2. Qualifying for services 3. Availability of services
Salmon (2008) **New Zealand**	Describe the lived experiences of biological mothers, from pregnancy onwards, of a child/ren diagnosed with FASD	8 biological mothers who had nurtured or were still living with their offspring (aged 8.5 to 30 years) diagnosed with FASD	Unstructured individual interviews; constant comparative method, validity: triangulation	1. Medical and health professionals abandon the mothers
Sanders and Buck (2010) **Canada**	Investigate parents' experiences raising children with FASD	11 caregivers (3 biological, 7 adoptive, 1 foster) of individuals (aged 5 to 21 years) with FASD	Unstructured individual interviews; thematic analysis	1. Something's not right 2. Receiving a diagnosis
Temple et al. (2021) **Canada**	To understand how receiving a diagnosis of FASD in adulthood might influence outcomes; and investigate the long-term outcomes for individuals diagnosed with FASD after 18 years of age	20 adults (aged 18-45 years) who were referred to a diagnostic clinic and received an FASD after 18 years of age	Survey (open-ended questions); qualitative analysis	1. Reactions and thoughts about receiving an FASD diagnosis

Thomas and Mukherjee (2019) **U.K**	Explore experiences of biological mothers following a diagnosis of FASD in their children	5 biological mothers of children with FASD (age from 10-29 years).	Individual semi-structured interviews; Interpretative phenomenological analytical approach	1. Life is a series of battles
Watson et al. (2013) **Canada**	Examine the experience of raising a child with a disability	31 parents (biological parents, foster parents, adoptive parents, step-parents and custodial grandparents) of children with FASD (aged from 1-36 years)	Semi-structured interviews (individually or couples), follow-up questions by email or telephone; interpretative phenomenological analysis	1. The FASD diagnostic process 2. A family's need for a label

[a]Hamilton et al. (2020) presented results as vignettes. Main themes presented in this table have been summarised by the review authors drawing on information presented in the vignettes.

Table 2. Quality assessment of included studies.

CASP Qualitative Checklist	Chamberlain et al., 2017	Doak et al., 2019	Duquette & Stodel, 2005	Hamilton et al., 2020	Petrenko et al., 2014	Salmon, 2008	Sanders & Buck, 2010	Temple et al., 2020	Thomas & Mukherjee, 2019	Watson et al., 2013
Clear statement of aim	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative methodology	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Research design	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sampling	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Data collection	Yes	Yes	Yes	Yes	Yes	Partial	Unclear	Yes	Yes	Yes

Researcher reflexivity	Partial	Partial	No	Partial	No	No	No	No	No	No
Ethical consideration	Yes	Yes	Unclear	Yes	Yes	Yes	Partial	Yes	Yes	Yes
Data analysis	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	Partial	Yes
Clear statement of findings	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Research value	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 3. Review findings and GRADE-CERQual ratings.

Review Findings	GRADE-CERQual assessment		
	Contributing Studies	**Confidence Rating**	**Explanation**
Pre-Assessment Concerns and Challenges			
Caregiver recognition and help-seeking for child's challenges: Caregivers reported recognising behavioural challenges that prompted them to seek help. Challenges included oppositional defiance, aggression and severe impulsivity.	3 studies (Chamberlain et al., 2017; Salmon, 2008; Sanders & Buck, 2010)	Moderate	Rated down one level due to minor concerns related to methodology limitations of the contributing studies, minor concerns about coherence across studies, and minor concerns related to assessment of adequacy due to small sample size and limited data.
Dismissal of caregiver's concerns by health professionals: Caregivers perceived previous health services to be unhelpful and, in some cases, negative, including not feeling listened to and having their concerns dismissed	3 studies (Chamberlain et al., 2017; Salmon, 2008; Sanders & Buck, 2010)	High	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.
FASD not considered or acknowledged: Caregivers reported that FASD was not considered as a possible diagnostic outcome, even when caregivers raised the topic of PAE/FASD with health professionals.	7 studies (Doak et al., 2019; Duquette et al., 2005; Petrenko et al., 2014; Salmon, 2008; Sanders & Buck, 2010; Thomas & Mukherjee, 2019; Watson et al., 2013)	High	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.
Diagnostic Assessment Process			

Limited availability of diagnostic assessment services: Caregiver's described frustrations with accessing assessment services for FASD due to the limited number of and long waitlists when services were available.	3 studies (Petrenko et al., 2014; Thomas & Mukherjee, 2019; Watson et al., 2013)	Moderate	Rated down one level due to minor concerns related to methodology limitations, minor concerns about coherence of findings across studies, and minor concerns related to adequacy due to limited data.
A safe and supportive environment without judgement is validating and empowering: Caregivers reported positive experiences with high levels of satisfaction and feelings of empowerment when attending a specialist FASD service. This was attributed to welcoming, supportive interactions with clinic staff who were helpful, reassuring, and respectful without being judgemental or stigmatising.	2 studies (Chamberlain et al., 2017; Doak et al., 2019)	Moderate	Rated down one level due to very minor concerns related to methodological limitations, and minor concerns related to relevance of the samples and adequacy of the data, although no concerns related to coherence.
Strengths-based diagnostic reports are a valuable resource: The diagnostic reports were noted as a valuable resource by caregivers to help them and others working with their child to understand strengths and areas of vulnerability. Caregivers reported intentions to share reports with future health professionals, social services, youth justice personnel, and school staff.	3 studies (Chamberlain et al., 2017; Doak et al., 2019; Hamilton et al., 2020)	High	Did not rate down. Very minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.
Receiving the Diagnosis			
Mixed emotions and improved insight: While mixed feelings were experienced when receiving a FASD diagnosis, including a sense of relief, hope and confidence, as well as grief, hopelessness, guilt and shame, the diagnosis also provided improved understanding and insight	8 studies (Chamberlain et al., 2017; Doak et al., 2019; Duquette et al., 2005; Hamilton et al., 2020; Sanders & Buck, 2010; Temple et al., 2020; Thomas & Mukherjee, 2019; Watson et al., 2013)	High	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.

Means to receive appropriate and tailored support: Adult individuals and caregivers perceived the benefits of the diagnosis as a means to access appropriate support and services tailored to their own/their child's needs	6 studies (Chamberlain et al., 2017; Doak et al., 2019; Duquette et al., 2005; Hamilton et al., 2020; Temple et al., 2020; Watson et al., 2013)	High	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.
Post-Assessment Adaptations and Needs			
Aspirations and apprehensions about the future: Caregivers recognised their child's strengths, and with appropriate support, expressed aspirations for a fulling life for their child. At the same time, caregivers expressed apprehension about their child's future, acknowledging uncertainties related to ongoing difficulties and complexities of secondary conditions.	2 studies (Chamberlain et al., 2017; Doak et al., 2019)	Moderate	Rated down one level due to minor concerns related to methodological limitations and adequacy. No concerns related to relevance or coherence.
Accessing supports and services: Caregivers described various service- and family-level barriers in accessing post-assessment support, including a lack of local FASD-specific services and providers knowledgeable in FASD and long waitlists for allied health services, as well as family and work commitments, financial strain and family stress.	5 studies (Chamberlain et al., 2017; Doak et al., 2019; Hamilton et al., 2020; Petrenko et al., 2014; Watson et al., 2013)	High	Did not rate down. Very minor concerns related to methodological limitations and minor concerns related to coherence, although no concerns related to relevance or adequacy.

Table 4. Summary of review findings and CERQual assessment of confidence in the evidence.

Review Theme	Studies contributing to the review findings	Methodological limitations	Relevance	Coherence	Adequacy	Overall Confidence in the Evidence	Explanation of Judgement
Pre-Assessment Concerns and Challenges							
Caregiver recognition and help-seeking for child's challenges	3 studies (Chamberlain et al., 2017; Salmon, 2008; Sanders & Buck, 2010)	**Minor concerns** All 3 studies had partial or no information on researcher reflexivity; 1 study had partial ethics considerations; 2 studies had partial/unclear data collection methods	**No concerns** 1 study from Australia, 1 study from New Zealand, 1 study from Canada Perspectives from range of caregivers were represented including biological, adoptive, foster and legal guardians. Individuals diagnosed with	**Minor concerns** Within studies: clear and cogent findings Across studies: minor inconsistency across studies – each described different behaviours and different ages of children.	**Minor concerns** Richness: limited data to gain understanding of phenomena described (1 study was a participant quote only; 1 study didn't provide any participant quotes) Quantity: 3 studies contributed, sample sizes ranged from 8-11, with total n of 29	**Moderate**	Rated down one level due to minor concerns related to methodology limitations, minor concerns about coherence of findings across studies, and minor concerns related to adequacy due to limited data and small sample size

			FASD ranged in age from 5-30yrs.				
Dismissal of caregiver's concerns by health professionals	3 studies (Chamberlain et al., 2017; Salmon, 2008; Sanders & Buck, 2010)	**Minor concerns** All 3 studies had partial or no information on researcher reflexivity; 1 study had partial ethics considerations; 2 studies had partial/unclear data collection methods	**No concerns** 1 study from Australia, 1 study from New Zealand, 1 study from Canada Perspectives from range of caregivers were represented including biological, adoptive, foster and legal guardians. Individuals diagnosed with FASD ranged in age from 5-30yrs.	**No concerns** Clear and cogent findings within and across studies	**Very minor concerns** Richness: sufficient data to gain understanding of phenomena described. Quantity: 3 studies contributed, sample sizes ranged from 8-11, with total n of 29	**High**	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.

FASD not considered or acknowledged	7 studies (Doak et al., 2019; Duquette & Stodel, 2005; Petrenko et al., 2014; Salmon, 2008; Sanders & Buck, 2010; Thomas & Mukherjee, 2019; Watson et al., 2013)	**Minor concerns** All 7 studies had partial or no information on researcher reflexivity; 2 studies had partial/unclear ethics considerations; 2 studies had partial/unclear data collection methods; 2 studies had unclear data analysis	**No concerns** 1 study from Australia, 3 studies from Canada, 1 study each from New Zealand, U.S. and U.K. Perspectives from a range of caregivers were represented (22 biological, 33 adoptive, 3 foster, 5 grandparents, 2 case/youth workers)[1] Individuals diagnosed with FASD ranged in age from 3-36yrs	**No concerns** Clear and cogent findings within and across studies	**No concerns** Richness: sufficient data to gain understanding of phenomena described. Quantity: 7 studies contributed, number of participants ranged from 5-31, total n of 97	**High**	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.
Diagnostic Assessment Process							
Limited availability of	3 studies (Petrenko et al., 2014; Thomas &	**Minor concerns**	**No concerns**	**Minor concerns**	**Minor concerns**	**Moderate**	Rated down one level due to minor concerns

diagnostic assessment services	Mukherjee, 2019; Watson et al., 2013)	All 3 studies had no information on research reflexivity; 1 study had partial information on data analysis	1 study each from Canada, U.S. and U.K. Perspectives from a range of caregivers were represented (6 biological mothers, 24 adoptive/foster parents)[1] Individuals diagnosed with FASD ranged in age from 3-36 years)	Within studies: clear and cogent findings Across studies: minor inconsistency across studies – each described different behaviours and different ages of children.	Richness: limited data to gain understanding of phenomena described Quantity: 3 studies contributed, number of participants ranged from 5 to 31, total n of 61		related to methodology limitations, minor concerns about coherence of findings across studies, and minor concerns related to adequacy due to limited data.
A safe and supportive environment without judgement is validating and empowering	2 studies (Chamberlain et al., 2017; Doak et al., 2019)	**Very minor concerns** Both studies had partial information on researcher reflexivity	**Minor concerns** 2 studies from Australia (limited geographic spread)	**No concerns** Clear and cogent findings within and across studies	**Minor concerns** Richness: data to gain understanding of phenomena described.	**Moderate**	Rated down one level due to very minor concerns related to methodological limitations, and minor concerns related to relevance of the samples and adequacy of the data, although

			Perspectives from a range of caregivers and were represented (4 biological, 1 adoptive, 4 foster, 5 legal guardians, 3 grandparents) Individuals with FASD ranged in age from 3-13yrs		Quantity: 2 studies contributed, number of participants ranged from 7-10, total n of 17		no concerns related to coherence.
Strengths-based diagnostic reports are a valuable resource	3 studies (Chamberlain et al., 2017; Doak et al., 2019; Hamilton et al., 2020)	**Very minor concerns** All 3 studies had only partial information on researcher reflexivity	**Very minor concerns** 3 studies from Australia (limited geographic spread) Perspectives from a range of caregivers were represented (10 biological, 1	**No concerns** Clear and cogent findings within and across studies	**No concerns** Richness: sufficient data to gain understanding of phenomena described. Quantity: 3 studies contributed, number of participants ranged from 7-15, total n of 32	**High**	Did not rate down. Very minor concerns related to methodological limitations and relevance, although no concerns related to coherence or adequacy.

			adoptive, 4 foster, 5 legal guardians, and 8 grandparents) Individuals with FASD ranged in age from 3-17yrs				
Receiving the Diagnosis							
Mixed emotions and improved insight	8 studies (Chamberlain et al., 2017; Doak et al., 2019; Duquette & Stodel, 2005; Hamilton et al., 2020; Sanders & Buck, 2010; Temple et al., 2020; Thomas & Mukherjee, 2019; Watson et al., 2013)	**Minor concerns** All 8 studies had partial or no information on researcher reflexivity; 2 studies had unclear ethics considerations; 1 study had unclear data collection methods and 3 studies had partial or unclear data analysis	**No concerns** 3 studies from Australia, 4 studies from Canada; 1 study from U.K. Perspectives from a range of caregivers and individuals diagnosed with FASD were represented (18 biological, 19 adoptive, 5 foster, 5 legal guardians, 8	**No concerns** Clear and cogent findings within and across studies	**No concerns** Richness: sufficient data to gain understanding of the phenomena described. 8 studies contributed, number of participants ranged from 7-31, total n of 105	**High**	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.

			grandparents, 20 adult individuals)[1] Individuals with FASD ranged in age from 1-45yrs				
Means to receive appropriate and tailored support	6 studies (Chamberlain et al., 2017; Doak et al., 2019; Duquette & Stodel, 2005; Hamilton et al., 2020; Temple et al., 2020; Watson et al., 2013)	**Minor concerns** All 6 studies had partial or no information on researcher reflexivity; 1 study had unclear ethics considerations; 2 studies had unclear data analysis	**No concerns** 3 studies from Australia, 3 studies from Canada Perspectives from a range of caregivers and individuals diagnosed with FASD were represented (11 biological, 14 adoptive, 6 foster, 5 legal guardians, 10 grandparents, and 20 adult individuals)[1]	**No concerns** Clear and cogent findings within and across studies	**No concerns** Richness: sufficient data to gain understanding of the phenomena described. Quantity: 6 studies contributed, sample sizes ranged from 7-31, total n of 104	**High**	Did not rate down. Minor concerns related to methodological limitations, although no concerns related to relevance, coherence or adequacy.

			Individuals with FASD ranged in age from 3-45yrs				
Post-Assessment Adaptions and Needs							
Aspirations and apprehensions about the future	2 studies (Chamberlain et al., 2017; Doak et al., 2019)	**Very minor concerns** Both studies had partial information on researcher reflexivity	**Minor concerns** 2 studies from Australia (limited geographic spread) Perspectives from a range of caregivers and were represented (4 biological, 1 adoptive, 4 foster, 5 legal guardians, 3 grandparents) Individuals with FASD ranged in age from 3-13yrs	**No concerns** Clear and cogent findings within and across studies	**Minor concerns** Richness: data to gain understanding of phenomena described. Quantity: 2 studies contributed, number of participants ranged from 7-10, total n of 17	**Moderate**	Rated down one level due to very minor concerns related to methodological limitations, minor concerns about relevance and the geographical representation, and minor concerns about adequacy of the data. No concerns related to coherence.

Accessing supports and services	5 studies (Chamberlain et al., 2017; Doak et al., 2019; Hamilton et al., 2020; Petrenko et al., 2014; Watson et al., 2013)	**Very minor concerns** All 5 studies had only partial information on researcher reflexivity	**No concerns** 3 studies from Australia, 1 study each from U.S. and Canada Perspectives from a range of caregivers were represented (12 biological, 27 adoptive, 6 foster, 5 legal guardians, 10 grandparents)[1] Individuals with FASD ranged in age from 1-36yrs	**Minor concerns** Within studies: clear and cogent findings Across studies: minor inconsistency across studies – reasons for lack of support varied across studies	**No concerns** Richness: sufficient data to gain understanding of phenomena described. Quantity: 5 studies contributed, sample sizes ranged from 7-31, total n of 98	**High**	Did not rate down. Very minor concerns related to methodological limitations and minor concerns related to coherence of findings across studies, although no concerns related to relevance or adequacy.

Note: Ratings for methodological limitations, relevancy, coherence and adequacy are no/very minor, minor, moderate, serious. Ratings for overall CERQual assessment are High, Moderate, Low, Very Low confidence. [1]Watson et al., 2013 did not provide n's for each caregiver type

5. Limitations of the Review

Limitations to consider when interpreting the findings:

- Review findings are constrained to the data provided by the interviews and participants within the published studies - only three studies specifically examined experiences of the FASD assessment and diagnostic process, while the other seven studies reported on these experiences as part of a larger aim to examine experiences of living with FASD. This is reflected in the low-moderate confidence ratings for the three themes relating to the diagnostic assessment process.
- Only a small number of studies discerned the perspective of biological caregivers, Indigenous caregivers, and adult clients, with no studies examining the perspectives of children/adolescents who undertook an assessment for FASD.
- There was limited geographical representation with most included studies conducted in Australia and Canada.

6. Linking to Lived Experience Guideline Statements

The following lived experience guideline statements were developed from this systematic review and used in the guidelines document. The guideline document defines these lived experience statements as actionable statements derived from an evidence synthesis of lived experience and reviewed by the Guidelines Development Group. They provide important guidance for health care providers to consider when providing assessment and diagnosis of FASD.

Guidelines Section: Assessment Process
Listen to and take seriously concerns raised by parents/caregivers about their child's development and behaviour in the context of prenatal alcohol exposure.
Provide or refer for assessment if a parent/caregiver is concerned about their child's development in the context of prenatal alcohol exposure.
To reduce barriers experienced by individuals and families, assessment can be provided across a range of settings. This includes, but is not limited to, specialist FASD/ND-PAE services, child development services, adolescent and adult private and public health services, primary care, mental health, disability, justice, and child protection services.
Provide non-judgemental and non-stigmatising support that acknowledges and respects the individual's and their parent/caregivers' experiences and concerns.
Guidelines Section: Holistic Formulation, Feedback, and Strengths-based Pathways
Understand that receiving a diagnosis can bring mixed emotions. Plan feedback and recommendations with this in mind.
Assessment results help understand behaviour. When communicating outcomes, provide specific information and examples clearly linking assessment results to observed or reported challenges in daily functioning to support understanding and insight.
Recognise both an individual's strengths and challenges to identify the most appropriate supports to enable positive outcomes post-assessment.
Be mindful that parents/caregivers and family members can have concerns regarding their child's future following diagnosis. Provide recommendations for specific local services that can provide emotional supports.
Tailor feedback sessions and reports to individual and family needs, including relevant social and cultural factors.
When writing reports, emphasise the individual's strengths and interests, while also addressing areas needing support.

When writing reports, prioritise recommendations that are important for the individual/family, and limit recommendations to those that are practical and achievable in their household and community.

7. References

7.1 Included studies

Chamberlain K, Reid N, Warner J, Shelton D, Dawe S (2017) A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. Res Dev Disabil 63:99-106.

Doak J, Katsikitis M, Webster H, Wood A (2019) A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. Res Dev Disabil 93:103428.

Duquette C, Stodel EJ (2005) School experiences of students with fetal alcohol spectrum disorder. Exceptionality Educ Canada 15:51-75.

Hamilton SL, Maslen S, Watkins R, Conigrave K, Freeman J, O'Donnell M, Mutch RC, Bower C (2020) 'That thing in his head': Aboriginal and non-Aboriginal Australian caregiver responses to neurodevelopmental disability diagnoses. Sociol Health Illn 42:1581-1596.

Petrenko CL, Tahir N, Mahoney EC, Chin NP (2014) Prevention of secondary conditions in fetal alcohol spectrum disorders: identification of systems-level barriers. Matern Child Health J 18:1496-1505.

Salmon J (2008) Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. Can J Clin Pharmacol 15:e191-213.

Sanders JL, Buck G (2010) A long journey: Biological and non-biological parents' experiences raising children with FASD. Journal of Population Therapeutics and Clinical Pharmacology 17:e308-e322.

Temple VK, Prasad S, Popova S, Lindsay A (2021) Long-term outcomes following Fetal Alcohol Spectrum Disorder (FASD) diagnosis in adulthood. Journal of Intellectual & Developmental Disability 46:272-280.

Thomas R, Mukherjee R (2019) Exploring the experiences of birth mothers whose children have been diagnosed with fetal alcohol spectrum disorders: a qualitative study. Adv Dual Diagn 12:27-35.

Watson SL, Hayes SA, Coons KD, Radford-Paz E (2013) Autism spectrum disorder and fetal alcohol spectrum disorder. Part II: A qualitative comparison of parenting stress. J Intellect Dev Disabil 38:105-113.

7.2 Other references

Critical Appraisal Skills Programme. CASP Qualitative Studies Checklist. Available at www.casp-uk.net/casp-tools-checklists/. Accessed 6 June 2021.

Lewin S, Glenton C, Munthe-Kaas H, Carlsen B, Colvin CJ, Gülmezoglu M, Noyes J, Booth A, Garside R, Rashidian A (2015) Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). PLoS Med 12:e1001895.

Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R, Glanville J, Grimshaw JM, Hróbjartsson A, Lalu MM, Li T, Loder EW, Mayo-Wilson E, McDonald S, McGuinness LA, Stewart LA, Thomas J, Tricco AC, Welch VA, Whiting P, Moher D (2021) The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 372:n71.

Thomas J, Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol 8:45.

Appendix 1

Appendix Table 1. Studies Excluded at Full-Text

Reference	Reasoning
Alex, K., & Feldmann, R. (2012). Children and adolescents with fetal alcohol syndrome (FAS): better social and emotional integration after early diagnosis. *Klin Padiatr*, *224*(2), 66-71. https://doi.org/10.1055/s-0031-1299682	Not lived experience (not perspective of parent, carer, family, individual etc)
Anderson, T., Mela, M., Rotter, T., & Poole, N. (2019). A Qualitative Investigation into Barriers and Enablers for the Development of a Clinical Pathway for Individuals Living with FASD and Mental Disorder/Addictions. *Canadian Journal of Community Mental Health*, *38*(3), 43-60. https://doi.org/10.7870/cjcmh-2019-009	Full-text not available
Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol*, *17*(1), e132-164.	Not lived experience (not perspective of parent, carer, family, individual etc)
Baskin, J., Delja, J. R., Mogil, C., Gorospe, C. M., & Paley, B. (2016). Fetal Alcohol Spectrum Disorders and Challenges Faced by Caregivers: Clinicians' Perspectives. *J Popul Ther Clin Pharmacol*, *23*(2), e114-130.	Not lived experience (not perspective of parent, carer, family, individual etc)
Bobbitt, S. A., Baugh, L. A., Andrew, G. H., Cook, J. L., Green, C. R., Pei, J. R., & Rasmussen, C. R. (2016). Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder. *Res Dev Disabil*, *55*, 100-113. https://doi.org/10.1016/j.ridd.2016.03.002	No outcomes of interest (not about diagnostic/assessment process)
Brown, J. D. Sigvaldason, N. & Bednar, L. A. (2005). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder, *Children and Youth Services Review, 27*(3), 309-327.	No outcomes of interest (not about diagnostic/assessment process)
Brown, J. D. (2004). Family supports for children who have alcohol-related disabilities. *Developmental Disabilities Bulletin*, *32*(1), 44-61.	Literature review only (is not a research study or review of research studies
Brown, J. D., & Bednar, L. M. (2003). Parenting children with fetal alcohol spectrum disorder: A concept map of needs. *Developmental Disabilities Bulletin*, *31*(2), 130-154.	Full-text not available
Burnside, L., & Fuchs, D. (2013). Bound by the clock: The experiences of youth with FASD transitioning to adulthood from child welfare care. *First Peoples Child & Family Review*, *8*(1), 40-61. <Go to ISI>://WOS:000213541100006	No outcomes of interest (not about diagnostic/assessment process)
Caley, L. M., Winkelman, T., & Mariano, K. (2009). Problems expressed by caregivers of children with fetal alcohol spectrum disorder. *Int J Nurs Terminol Classif*, *20*(4), 181-188. https://doi.org/10.1111/j.1744-618X.2009.01133.x	Not lived experience (not perspective of parent, carer, family, individual etc)

Clark, E., Minnes, P., Lutke, J., & Ouellette-Kuntz, H. (2008). Caregiver perceptions of the community integration of adults with foetal alcohol spectrum disorder in British Columbia. *Journal of Applied Research in Intellectual Disabilities*, *21*(5), 446-456. https://doi.org/10.1111/j.1468-3148.2007.00414.x	Not lived experience (not perspective of parent, carer, family, individual etc)
Coons, K. D., Watson, S. L., Schinke, R. J., & Yantzi, N. M. (2016). Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: What has helped. *J Intellect Dev Disabil*, *41*(2), 150-165. https://doi.org/10.3109/13668250.2016.1156659	No outcomes of interest (not about diagnostic/ assessment process)
Coons, K. D., Watson, S. L., Yantzi, N. M., & Schinke, R. J. (2018). Adaptation in families raising children with fetal alcohol spectrum disorder. Part II: What would help. *J Intellect Dev Disabil*, *43*(2), 137-151. https://doi.org/10.3109/13668250.2016.1267718	No outcomes of interest (not about diagnostic/ assessment process)
Corrigan, P. W., Shah, B. B., Lara, J. L., Mitchell, K. T., Combs-Way, P., Simmes, D., & Jones, K. L. (2019). Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder. *Addiction Research & Theory*, *27*(2), 170-177. https://doi.org/10.1080/16066359.2018.1478413	No outcomes of interest (not about diagnostic/ assessment process)
Currie, B. A., Hoy, J., Legge, L., Temple, V. K., & Tahir, M. (2016). Adults with Fetal Alcohol Spectrum Disorder: Factors Associated with Positive Outcomes and Contact with the Criminal Justice System. *J Popul Ther Clin Pharmacol*, *23*(1), e37-52	No outcomes of interest (not about diagnostic/assessment process)
Devries, J., & Waller, A. (2004). Fetal alcohol syndrome through the eyes of parents. *Addict Biol*, *9*(2), 119-126.	Literature review only (is not a research study or review of research studies
Doig, J. L., McLennan, J. D., & Urichuk, L. (2009). 'Jumping through hoops': parents' experiences with seeking respite care for children with special needs. *Child Care Health Dev*, *35*(2), 234-242.	No outcomes of interest (not about diagnostic/assessment process)
Domeij, H., Fahlström, G., Bertilsson, G., Hultcrantz, M., Munthe-Kaas, H., Gordh, C. N., & Helgesson, G. (2018). Experiences of living with fetal alcohol spectrum disorders: a systematic review and synthesis of qualitative data. *Dev Med Child Neurol*, *60*(8), 741-752.	No outcomes of interest (not about diagnostic/assessment process)
Duquette, C., & Orders, S. (2013). On fitting a triangle into a circle: A study on employment outcomes of adults with Fetal Alcohol Spectrum Disorder who attended postsecondary institutions. *International Journal of Alcohol and Drug Research*, *2*(3), 27-36.	No outcomes of interest (not about diagnostic/assessment process)
Duquette, C., & Stodel, E. J. (2005). School experiences of students with Fetal Alcohol Spectrum Disorder. *Exceptionality Education Canada*, *15*(2), 51-75.	Full-text not available
Fry-Johnson, Y. (2008). Foetal alcohol spectrum disorders: Diagnoses impact a lifetime for affected individuals, families and communities. *Journal of Intellectual Disability Research*, *52*, 738-738.	Not appropriate article type (abstract, book chapter)
Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *MCN Am J Matern Child Nurs*, *25*(5), 252-257.	No outcomes of interest (not about diagnostic/assessment process)

Hamilton, S., Reibel, T., Maslen, S., Watkins, R., Jacinta, F., Passmore, H., Mutch, R., O'Donnell, M., Braithwaite, V., & Bower, C. (2020). Disability "In-Justice": The Benefits and Challenges of "Yarning" With Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center. *Qual Health Res*, *30*(2), 314-327.	No outcomes of interest (not about diagnostic/assessment process)
Helgesson, G., Bertilsson, G., Domeij, H., Fahlström, G., Heintz, E., Hjern, A., Nehlin Gordh, C., Nordin, V., Rangmar, J., Rydell, A. M., Wahlsten, V. S., & Hultcrantz, M. (2018). Ethical aspects of diagnosis and interventions for children with fetal alcohol Spectrum disorder (FASD) and their families. *BMC Med Ethics*, *19*(1).	Not appropriate article type (abstract, book chapter)
Jones, H. M., McKenzie, A., Miers, S., Russell, E., Watkins, R. E., Payne, J. M., Hayes, L., Carter, M., D'Antoine, H., Latimer, J., Wilkins, A., Mutch, R. C., Burns, L., Fitzpatrick, J. P., Halliday, J., O'Leary, C. M., Peadon, E., Elliott, E. J., & Bower, C. (2013). Involving consumers and the community in the development of a diagnostic instrument for fetal alcohol spectrum disorders in Australia. *Health Res Policy Syst*, *11*, 26.	No outcomes of interest (not about diagnostic/assessment process)
Kapasi, A., & Brown, J. (2017). Strengths of caregivers raising a child with foetal alcohol spectrum disorder. *Child & Family Social Work*, *22*(2), 721-730.	No outcomes of interest (not about diagnostic/assessment process)
Kapasi, A., Makela, M. L., Hannigan, K., Joly, V., & Pei, J. R. (2019). Understanding employment success in adults with Fetal Alcohol Spectrum Disorder. *Journal of Vocational Rehabilitation*, *51*(3), 377-393.	Full-text not available
Knorr, L., & McIntyre, L. J. (2016). Resilience in the face of adversity: Stories from adults with fetal alcohol spectrum disorders. *Exceptionality Education International*, *26*(1), 53-75.	Full-text not available
McDougall, S., Finlay-Jones, A., Arney, F., & Gordon, A. (2020). A qualitative examination of the cognitive and behavioural challenges experienced by children with fetal alcohol spectrum disorder. *Res Dev Disabil*, *104*, 103683.	No outcomes of interest (not about diagnostic/assessment process)
McFarlane, A. (2011). Fetal alcohol spectrum disorder in adults: diagnosis and assessment by a multidisciplinary team in a rural area. *Canadian Journal of Rural Medicine*, *16*(1), 25-30.	Not lived experience (not perspective of parent, carer, family, individual etc)
McLachlan, K., Andrew, G., Pei, J., & Rasmussen, C. (2015). Assessing FASD in young children: Exploring clinical complexities and diagnostic challenges. *Journal of Population Therapeutics and Clinical Pharmacology*, *22*(1), E108-E124.	Not lived experience (not perspective of parent, carer, family, individual etc)
McLachlan, K., Flannigan, K., Temple, V., Unsworth, K., & Cook, J. L. (2020). Difficulties in Daily Living Experienced by Adolescents, Transition-Aged Youth, and Adults With Fetal Alcohol Spectrum Disorder. *Alcohol Clin Exp Res*, *44*(8), 1609-1624.	No outcomes of interest (not about diagnostic/ assessment process)
McRae, T., Adams, E., Clifton, E., Fitzpatrick, J., Bruce, K., Councillor, J., Pearson, G., & Walker, R. (2019). Overcoming the challenges of caring for a child with foetal alcohol spectrum disorder: a Pilbara community perspective. *Rural Remote Health*, *19*(4), 5206.	No outcomes of interest (not about diagnostic/assessment process)

Meurk, C., Lucke, J., & Hall, W. (2014). A Bio-Social and Ethical Framework for Understanding Fetal Alcohol Spectrum Disorders. *Neuroethics*, *7*(3), 337-344.	Literature review only (is not a research study or review of research studies)
Michaud, D., & Temple, V. (2013). The complexities of caring for individuals with fetal alcohol spectrum disorder: The perspective of mothers. *Journal on Developmental Disabilities*, *19*(3), 94-101.	No outcomes of interest (not about diagnostic/ assessment process)
Mitten, H. R. (2013). EVIDENCE-BASED PRACTICE GUIDELINES FOR FETAL ALCOHOL SPECTRUM DISORDER AND LITERACY AND LEARNING. *International Journal of Special Education*, *28*(3), 44-57.	No outcomes of interest (not about diagnostic/assessment process)
Mohamed, Z., Carlisle, A. C. S., Livesey, A. C., & Mukherjee, R. A. S. (2020). Carer stress in Fetal Alcohol Spectrum Disorders: the implications of data from the UK national specialist FASD clinic for training carers. *Adoption and Fostering*, *44*(3), 242-254.	Not lived experience (not perspective of parent, carer, family, individual etc)
Mukherjee, R., Wray, E., Commers, M., Hollins, S., & Curfs, L. (2013). The impact of raising a child with FASD upon carers: findings from a mixed methodology study in the UK. *Adoption and Fostering*, *37*(1), 43-56.	No outcomes of interest (not about diagnostic/assessment process)
Patrenko, C. L., Tahir, N., Mahoney, E. C., & Chin, N. P. (2014). A qualitative assessment of program characteristics for preventing secondary conditions in individuals with fetal alcohol spectrum disorders. *J Popul Ther Clin Pharmacol*, *21*(2), e246-259	No outcomes of interest (not about diagnostic/assessment process)
Pei, J., & Rinaldi, C. (2004). A review of the evolution of diagnostic practices for Fetal Alcohol Spectrum Disorder. *Developmental Disabilities Bulletin*, *32*(2), 125-139.	Literature review only (is not a research study or review of research studies
Pepper, J., Watson, S., & Coons-Harding, K. D. (2019). “Well where’s he supposed to live?”—Experiences of adoptive parents of emerging adult children with FASD in Ontario. *Journal on Developmental Disabilities*, *24*(1), 66-80.	No outcomes of interest (not about diagnostic/assessment process)
Petrenko, C. L. M., Alto, M. E., Hart, A. R., Freeze, S. M., & Cole, L. L. (2019). "I'm Doing My Part, I Just Need Help From the Community": Intervention Implications of Foster and Adoptive Parents' Experiences Raising Children and Young Adults With FASD. *J Fam Nurs*, *25*(2), 314-347.	No outcomes of interest (not about diagnostic/ assessment process)
Pruner, M., Jirikowic, T., Yorkston, K. M., & Olson, H. C. (2020). The best possible start: A qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders. *Res Dev Disabil*, *97*, 103558.	No outcomes of interest (not about diagnostic/assessment process)
Reid, D., Laplante, S., Marnoch, R., Roberts, T., Noah, J., Schmidt, S., Beland, W., & Mohr, S. (2018). What it takes to support a loved one with FASD. *First Peoples Child & Family Review*, *13*(2), 14-14.	Not appropriate article type (abstract, book chapter)
Reid, N., Hawkins, E., Liu, W., Page, M., Webster, H., Katsikitis, M., Shelton, D., Wood, A., O'Callaghan, F., Morrissey, S., & Shanley, D. (2021). Yarning about fetal alcohol spectrum disorder: Outcomes of a community-based workshop. *Res Dev Disabil*, *108*, 103810.	No outcomes of interest (not about diagnostic/assessment process)

Reid, N., Kippin, N., Passmore, H., & Finlay-Jones, A. (2020). Fetal alcohol spectrum disorder: the importance of assessment, diagnosis and support in the Australian justice context. *Psychiatr Psychol Law*, *27*(2), 265-274.	Literature review only (is not a research study or review of research studies)
Richer, E., & Watson, S. L. (2018). "He's on the streets, and stealing, and perpetuating the cycle… and I'm helpless": Families' perspectives on criminality in adults prenatally exposed to alcohol. *Journal on Developmental Disabilities*, *23*(3), 90-104.	No outcomes of interest (not about diagnostic/ assessment process)
Rutman, D., & Van Bibber, M. (2010). Parenting with Fetal Alcohol Spectrum Disorder. *Int J Ment Health Addict*, *8*(2), 351-361	No outcomes of interest (not about diagnostic/assessment process)
Salmon, A. (2007). Dis/Abling States, Dis/Abling Citizenship: Young Aboriginal Mothers and the Medicalization of Fetal Alcohol Syndrome. *Journal for Critical Education Policy Studies*, *5*(2), 271-306.	No outcomes of interest (not about diagnostic/ assessment process)
Samaroden, M. (2018). Challenges and resiliency in Aboriginal adults with Fetal Alcohol Spectrum Disorder. *First Peoples Child & Family Review*, *13*(1), 8-19	Literature review only (is not a research study or review of research studies)
Sparrow, J., Grant, T., Connor, P., & Whitney, N. (2013). The value of the neuropsychological assessment for adults with Fetal Alcohol Spectrum Disorder: A case study. *International Journal of Alcohol and Drug Research*, *2*(3), 79-86.	Not lived experience (not perspective of parent, carer, family, individual etc)
Stade, B., Beyene, J., Buller, K., Ross, S., Patterson, K., Stevens, B., Sgro, M., Ungar, W., Watson, W., & Koren, G. (2011). Feeling different: the experience of living with fetal alcohol spectrum disorder. *J Popul Ther Clin Pharmacol*, *18*(3), e475-485.	No outcomes of interest (not about diagnostic/ assessment process)
Streissguth, A. P., & Giunta, C. T. (1988). Mental health and health needs of infants and preschool children with Fetal Alcohol Syndrome. *International Journal of Family Psychiatry*, *9*(1), 29-47.	Full-text not available;
Tait, C. L., Mela, M., Boothman, G., & Stoops, M. A. (2017). The lived experience of paroled offenders with fetal alcohol spectrum disorder and comorbid psychiatric disorder. *Transcult Psychiatry*, *54*(1), 107-124	No outcomes of interest (not about diagnostic/ assessment process)
Temple, V. K., Ives, J., & Lindsay, A. (2015). Diagnosing FASD in adults: the development and operation of an adult FASD clinic in Ontario, Canada. *J Popul Ther Clin Pharmacol*, *22*(1), e96-e105.	Not lived experience (not perspective of parent, carer, family, individual etc)
Todorow, M., Paris, K., & Fantus, E. (2012). Ethical considerations when communicating a diagnosis of a fetal alcohol spectrum disorder to a child. *J Popul Ther Clin Pharmacol*, *19*(3), e361-368.	Literature review only (is not a research study or review of research studies)
Toutain, S., & Lejeune, C. (2008). Family management of infants with fetal alcohol syndrome or fetal alcohol spectrum disorders. *Journal of Developmental and Physical Disabilities*, *20*(5), 425-436	No outcomes of interest (not about diagnostic/ assessment process)

Vepsa, K. H. Is it FASD? And does it matter? Swedish perspectives on diagnosing fetal alcohol spectrum disorders. *Drugs-Education Prevention and Policy*.	Not lived experience (not perspective of parent, carer, family, individual etc)
Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). "I'm hoping, I'm hoping..." Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities*, *19*(3), 76-93.	No outcomes of interest (not about diagnostic/ assessment process)
Whitehurst, T. (2012). Raising a child with foetal alcohol syndrome: hearing the parent voice. *British Journal of Learning Disabilities*, *40*(3), 187-193.	No outcomes of interest (not about diagnostic/ assessment process)
Whittingham, L. M., & Coons-Harding, K. D. (2020). Connecting People with People: Diagnosing Persons with Fetal Alcohol Spectrum Disorder Using Telehealth. *J Autism Dev Disord*.	Literature review only (is not a research study or review of research studies)
Winsor, K. D. An invisible problem: stigma and FASD diagnosis in the health and justice professions. *Advances in Dual Diagnosis*	Not lived experience (not perspective of parent, carer, family, individual etc)